

# AoA Caregiver Listserv: Respite Services for Caregivers

September 19 – October 3, 2001

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## INTRODUCTION

The fifth Administration on Aging (AoA) caregiver listserv session, “Respite Services for Caregivers,” was held from September 19 – October 3, 2001. This session provided the aging network participants the opportunity to exchange information about respite services for caregivers under the NFCSP. Steve Zarit, Assistant Director of the Gerontology Center at the Pennsylvania State University, served as the research resource for this session.

## BACKGROUND RESEARCH

The starting point for this session was an issue brief prepared by Zarit entitled, “Respite Services for Caregivers.” The paper covers available evidence of the effectiveness of respite services in alleviating the strain on caregivers of older people as well as practice implications for the aging network. Zarit notes that there is surprisingly little research on the effectiveness of respite services and although it seems obvious that respite services *should* be effective in lowering stress on caregivers, further research is needed to identify under what circumstances respite is effective. That is, there needs to be consideration of what type of programs are more effective, how much respite needs to be provided, and what specific benefits result. Some of Zarit’s findings from a review of the current empirical literature are:

- Benefits from respite services to caregivers are related to the amount of service delivered.
- Many caregivers do not use respite services, use only small amounts of respite, or use it only very late in the care process.
- The use of traditional care management to increase respite use among caregivers has been shown to produce only modest increases in respite use and little or no improvement in care-related stress among caregivers.
- Little evidence exists that respite services delay institutionalization or produce cost-savings. This might be partly due to caregivers using respite late in the care process, and in part because respite may not by itself, address the major causes of placement. Adult day services and overnight respite might actually facilitate placement in some cases by giving caregivers the emotional distance necessary to let go.

In terms of the practice implications for the aging network, Zarit offers the following:

- Respite services must be provided in sufficient amounts for caregivers to benefit.
- Remove barriers to obtaining respite that discourage families or limit the amount of service they are willing to use (i.e., bureaucratic rules for assigning families a “respite worker,” a service delivery time, or for determining financial assistance).

- A user-friendly system in which the consumer has control over the process may lead to improved utilization.
- Improve outreach to educate caregivers and the general public about the value of respite (consider collaborating with the Alzheimer's Association).
- Reexamine existing care management systems to determine how best to enhance care managers' skills in helping families understand the use of respite.
- Coordinate different types of respite services (adult day service, in-home, overnight) so that caregivers can put together a package of services if and when they need them.
- Partner with researchers to build a better foundation of practice knowledge to understand issues such as:
  - What are the barriers that families perceive and or encounter in the use of respite services?
  - What are the benefits and drawbacks of overnight respite for caregivers and clients?

\*The full paper as it appeared in this listserv session can be accessed through the AoA Web page, Implementing the National Family Caregiver Support Program, at:

<http://www.aoa.gov/carenetwork>. (Click on "Program Development Issue Briefs")

## **AGING NETWORK RESPONSES**

A SUA representative from **Alaska** reported that they are currently in the process of reviewing and revising their Respite Standards. She inquired about 1) models of consumer-directed respite programs and the rules/regulations that guide these programs, 2) trends in how respite is defined (e.g., broadly: "anything that provides relief" or more narrowly: "socialization and minor housekeeping activities"), 3) trends in criteria/eligibility for respite services, 4) and usage rates by different types of care recipients and caregivers by type of respite service (e.g., individuals with dementia and their caregivers, physically frail older adults). She directed participants to Alaska's In-Home Respite Standards and Adult Day Standards, found on their Web site at: [www.alaskaaging.org](http://www.alaskaaging.org) (click on "Home and Community Based Services" and then click on "Respite Standards or Adult Day Standards"), and welcomed comments or suggestions. Zarit recommended that the definition of respite services be kept broad to assure that creative approaches are supported and so that respite can be combined with other kinds of caregiver assistance.

An AAA representative from **Illinois** described her agency's approach to supporting caregivers with respite services. They are funding all types of respite for caregivers as defined by the NFCSP, including the qualification that the care recipient must need assistance with a minimum of two ADLs. In-home respite can include a homemaker, senior companion, or other care in the home, as long as it is not paid for by other state or federal funding. For daytime respite, they will also fund Child or Adult day services, as long as they are not paid for by insurance, the Illinois Community Care Program or a similar program for children eighteen years and younger. They have two senior "guest" houses in their area that will accept older

adults from any county in the PSA for overnight (or longer) respite stays. The AAA will also be providing respite for grandparent/kin caregivers if their care recipient also meets the NFCSP definitions. They will cap the annual amount of respite at \$750 per caregiver in order to serve as many individuals as possible. Their existing Case Coordination Units (CCUs) assess the care recipient for ADL needs and coordinate respite services for the caregiver. Funds are to be reimbursed to the CCU, not the caregiver. The AAA is encouraging interfaith coalitions to seek Robert Wood Johnson Foundation funding for volunteer respite programs (go to <http://www.fiavolunteers.org/> for more information and an application) and the AAA is willing to partner with them and assist with administrative costs of the new programs. The AAA is working to coordinate the assessment of caregivers and care recipients (around the ADL limitations) and is considering to adapt an existing instrument such as that used by Pennsylvania (found on AoA's NFCSP Web page, <http://www.aoa.gov/carenetwork> and click on "Resources and Tools").

The IL representative asked if there are available tools that are simple, time-effective, and cost-effective to measure respite service outcomes. Zarit noted that it is useful and practical to use research methods in practice settings as part of an evaluation that can inform the agency about strengths and weaknesses in the current approach. He emphasized that care recipients and their families are typically willing to complete research instruments because most people enjoy the opportunity to offer their opinion and it allows them to reflect about their situation. Zarit recommended that agencies partner with researchers from local universities who can work with them to generate an appropriate evaluation instrument.